Swiss Childhood Cancer Registry
Schweizer Kinderkrebsregister
Registre Suisse du Cancer de l'Enfant
Registro Svizzero dei Tumori Infantili

UNIVERSITÄT BERN

Jahresbericht
Rapport annuel
Relazione annuale

Annual Report 2005/2006

Swiss Childhood Cancer Registry

Annual Report 2005/2006

Gisela Michel
Nicolas von der Weid
Martin Adam
Cornelia E. Rebholz
Marcel Zwahlen
Claudia Kuehni

Bern, May 2007

Publisher: Swiss Childhood Cancer Registry
(Dr. med. Claudia Kuehni)

Address:
Dept. of Social and Preventive Medicine
University of Bern
Finkenhubelweg 11
CH-3012 Bern
Switzerland

Phone: +41 31 631 38 99
Fax: +41 31 631 35 20
e-mail : kinderkrebsregister@ispm.unibe.ch

Homepage: www.kinderkrebsregister.ch
Logo: Elsbeth Kuehni

Bern, Swiss Childhood Cancer Registry

1 Introduction

The Swiss Childhood Cancer Registry is the national cancer registry for children in Switzerland. It is a population-based registry with integrated clinical data. In February 2005, the SCCR became an associate member of the International Association of Cancer Registries (IACR) and the European Network of Cancer Registries (ENCR). Since 1976, all Swiss hospitals treating paediatric cancer patients (9 hospitals) report newly diagnosed children to the registry. With the long-term follow up of these children, survival, late effects and secondary tumours are being studied. Data are collected by all clinicians caring for children with cancer in Switzerland, who are organised in the Swiss Paediatric Oncology Group (SPOG; clinics in Aarau, Basel, Bern, Geneva, Lausanne, Lucerne, St. Gallen, Locarno, Zurich).

The SCCR collaborates with the Association of Swiss Cancer Registries (VSKR), the German Childhood Cancer Registry (GCCR), the National Registry of Childhood Tumours in the UK in Oxford (NRCT) and other national childhood cancer registries.

In this second Annual Report we present a description of the organisation and staff of the SCCR at the Institute of Social and Preventive Medicine (University of Bern) and the participating paediatric haematology-oncology clinics of the SPOG (chapter 2), and we present a summary of the data collected in the registry (chapter 3). Chapter 4 describes the research projects of the SCCR, together with an overview of the nested projects, for which the SCCR extracted datasets or provided analyses. A review of the activities of the SCCR in 2005 and 2006 can be found in chapter 5. To conclude this annual report, a list of the latest publications is given in chapter 6.

A detailed description of the history of the SCCR can be found in the annual report 2004 (download at: www.kinderkrebsregister.ch).

We would like to thank the SPOG clinicians and datamanagers for all their work for the SCCR, and the firms who are generously supporting the work of the SCCR.

2 Organisation of the Swiss Childhood Cancer Registry

2.1 Staff

The Swiss Childhood Cancer Registry (SCCR) is run jointly by the Swiss Paediatric Oncology Group (SPOG) and the Institute of Social and Preventive Medicine (ISPM) at the University of Bern.

2.1.1 Institute of Social and Preventive Medicine (ISPM), University of Bern

Finkenhubelweg 11, 3012 Bern,
Tel: +41 (0)31 631 38 99, Fax: +41 (0)31 631 35 20,
e-mail: kinderkrebsregister@ispm.unibe.ch

Management of the SCCR		
Dr. med. Claudia Kuehni FMH (Paediatrics), MSc (Epidemiology)	Overall responsibility	kuehni@ispm.unibe.ch
Dr. phil. Gisela Michel, PhD	Project Management	michel@ispm.unibe.ch
Scientific Staff		
Dr. med. Elisabeth Kiraly	Diagnostic Coding	kiraly@ispm.unibe.ch
Marie-Pierre Strippoli MSc (Med Stats)	Statistics	strippol@ispm.unibe.ch
Martin Adam, Sc.nat. ETH	Research project: Completeness of cancer registration and diagnostic accuracy in the SCCR	madam@ispm.unibe.ch
Cornelia E. Rebholz, Sc.nat. ETH	Research project: Long-term outcome of childhood cancer: incidence and spectrum of late effects	crebholz@ispm.unibe.ch
Administration and Computer Science		
Malcolm Sturdy	Computer Science	sturdy@ispm.unibe.ch

2.1.2 Swiss Paediatric Oncology Group (SPOG)

SIAK Koordinationszentrum, Effingerstrasse 40, 3008 Bern,
Fax: +41 (0)31 389 92 00

SPOG Executive		
PD Dr. med. Nicolas von der Weid	President	Nicolas.Von-Der-Weid@chuv.ch
Prof. Dr. med. Felix Niggli	Vice President	felix.niggli@kispi.unizh.ch
Dr. med. Heinz Hengartner	Secretary	heinz.hengartner@kispsisg.ch
Central Office in Bern		
Liselotte Lang (until March 2007)	Central administration	liselotte.lang@siak.ch
Barbara Kindler (since April 2007)	Central administration	barbara.kindler@sakk.ch
Friedgard Julmy	Clinical trials, ethic committee submissions	friedgard.julmy@insel.ch

Participating Clinics (Haemato-oncology)	Head of Division	Local Data-Manager
Aarau (Kinderklinik Kantonsspital Aarau):	Dr. med. R. Angst	Dr. med. R. Angst
Basel (Universitätskinderspital beider Basel):	Prof. Dr. med. M. Paulussen	V. Stahel
Bern (Universitäts-Kinderklinik Inselspital):	Prof. Dr. med. A. Hirt	K. Zimmermann
Geneva (Hôpital des Enfants):	PD Dr. med. A.H. Ozsahin	M. Berner
Lausanne (Service de Pédiatrie CHUV):	Dr. med. M. Beck-Popovic PD Dr. med. N. von der Weid	Dr. med. R. M. Garcia
Locarno (Reparto di Pediatria, Ospedale Regionale di Locarno):	Dr. med. L. Nobile	Dr. med. L. Nobile
Lucerne (Kantonspital Luzern, Kinderspital):	Dr. med. U. Caflisch	S. Ettlin
St. Gallen (Ostschweiz. Kinderspital):	Dr. med. J. Greiner	R. Fussenegger
Zurich (Universitäts-Kinderklinik Zürich):	Prof. Dr. med. F. Niggli	H. Markievicz

2.2 General information

The SCCR is an associate member of the International Association of Cancer Registries (IACR) and the European Network of Cancer Registries (ENCR).

2.2.1 Inclusion criteria and data collection

The SCCR includes the following diagnoses: i) Acute and chronic leukaemias, including myelodysplastic syndrome, ii) All solid malignancies, iii) All central nervous system tumours (CNS), including benign tumours, iv) Langerhans cell histiocytocis and other histiocytoses (type I–III). We aim for complete registration of all children below the age of 16 years who are diagnosed with cancer at one of the nine Swiss clinics for paediatric oncology and haematology. Occasionally older patients who are suffering from a paediatric cancer and are treated at these 9 clinics are also registered but unsystematically, as are children who are not residents of Switzerland but come here for treatment (these patients are not included in the analyses of incidence). Follow-up data is extracted once or twice a year from the patients' hospital records for the first 5 years after diagnosis. Thereafter follow-up data are obtained from the patients' general practitioners or paediatricians. In each of the nine centres a local data manager completes the data forms. These are sent to the central office of the SPOG; forwarded to the SCCR and entered into the database. Paper copies are stored at the SPOG central administration.

2.2.2 Current database

The electronic database of the SCCR which is currently in use has been developed by PD Dr. Nicolas von der Weid in 1992. At present, the database contains the following information on cancer patients:

- Patient's name, current address, and phone number, and address at the time of diagnosis.
- Name and address of the general practitioner or paediatrician and the paediatric oncology clinic treating the child.
- Demographic information (date of birth, gender)
- Socio-economic information (parental profession, place of origin, country of residence)
- Tumour diagnosis, date of diagnosis, type of cancer, histology, stage, metastases
- Other diagnoses, relevant pre-existing disease conditions
- Clinical information and laboratory values

- Treatment (treatment protocols, medication and dosages, radiotherapy, surgical interventions, others)
- Follow-up data concerning change of treatment, remission, relapses, survival/death and cause of death
- Late effects due to malignancy and therapy

A new electronic database is currently being programmed and will commence operation in July 2007. A detailed description will be available in the next annual report.

2.2.3 Tumour coding

Until 2004, all tumours were coded according to the coding used by the American Paediatric Oncology Group (POG). In addition, the exact diagnosis including details on location and staging was recorded.

In 2004 the SCCR started to code new tumours according to the following international classifications (see Appendix 1):

1. The third edition of the International Classification of Childhood Cancer (ICCC-3)[1]
2. The third edition of the International Classification of Diseases for Oncology (ICD-O-3)[2]
3. The tenth edition of the International Statistical Classification of Diseases and Related Health Problems (ICD-10)[3].

In 2006, all tumours contained in the database were double-coded by two physicians according to the three classification systems shown above.

To present data in the annual report the following classification for general diagnostic groups – a summary from the ICCC-3 classification – has been used: I. Leukaemias, II. Lymphomas, III. CNS tumours, IV. Sympathetic Nervous System (SNS) tumours, V. Retinoblastoma, VI. Renal tumours, VII. Hepatic tumours, VIII. Bone tumours, IX. Soft Tissue Sarcomas (STS) X. Germ cell tumours, XI. Carcinomas, XII. Other neoplasms. In addition, Langerhans cell histiocytoses are reported.

[1] Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, third edition. Cancer 2005;103(7):1457-67.

[2] World Health Organization. International Statistical Classification of Diseases for Oncology - 3rd Edition (ICD-O-3). Geneva: World Health Organization; 2000.

[3] World Health Organization. International statistical classification of diseases and related health problems - Tenth Edition. Geneva: World Health Organization; 1993.

3 Routine analyses

Up to December 31 2005 a total of 5014 tumour cases have been registered (4406 being Swiss residents). Known Swiss residents accounted for 87.9 % of all patients, and foreign residents treated in Switzerland for 9.6% (see Table 1). For retinoblastoma 52.8% (134/254) of cases were foreign residents. This is mainly due to the Jules Gonin Eye Hospital at the University Hospital in Lausanne, which has treated 170 of the total 254 cases of retinoblastoma.

When comparing the results of this year's analyses to the ones published in the previous annual report, there are some small differences in the numbers. Because the SCCR is a dynamic registry this is to be expected and is caused by occasional later additions and corrections of cases. In addition, all tumours were retrospectively classified according to ICCC-3, which might have caused a small modification in the exact diagnostic code (see 2.2.3 Tumour coding).

Systematic registration of all patients participating in clinical trials started in 1976 and the number of patients registered per year increased considerably after non-trial patients were included in 1981. After 1994 annual registration increased only very slightly. Between 2001 and 2005, there were about 217 new cases each year (about 203 of them Swiss residents (including Langerhans cell histiocytosis, LCH); Figure 1 and Table 2).

For the remaining analyses only Swiss residents aged under 15 years with a diagnosis according to ICCC-3 or LCH are included.

1006 patients were reported to have died and 681 patients are lost to follow-up. For 1434 patients (34.8%) the latest follow-up information was reported after 31 December 2002 and for 141 patients the latest information comes from the time between 2000 and 2002 (see Table 3).

Nearly half of the cases (47%) have been diagnosed at age 4 years or less, 10.4 % at less than 1 year of age and 36.6% between 1-4 years of age (Table 4 and Figure 2). The number of cases per age group declined from infancy to age 8 years and began to increase again until age 13 (Figure 3 and Figure 4).

One third of childhood cancers diagnosed in Swiss children between 1996 and 2005 were leukaemias (32.5%), followed by tumours of the central nervous system (CNS-tumours, 23.0%) and lymphomas (12.2%). Details of each diagnostic code (ICCC-3) for all Swiss patients diagnosed until 31 Dec 2005 are shown in Table 5 and Figure 5; details of the diagnosis for Swiss patients aged under 15 years and diagnosed in the last 10 years (between 1996 and 2005) are given in Table 6.

As found in other childhood cancer registries there was a higher number of boys than girls. This was true for most types of tumours with the exception of neuroblastomas, germ cell neoplasms and other malignant and epithelial tumours (Table 6).

The distribution of patients among the 9 SPOG clinics is shown in Table 7, Table 8, and Table 9. In 2005 most patients were treated in Zurich, followed by Lausanne and Bern.

The age-standardized incidence of any childhood cancer (not including LCH) in the past 5 years was 15.7 cases per 100'000 person/years in Switzerland (age-standardization according to the world population for the age-groups under 15 years[4]). Age adjusted incidence was highest among children aged less than 1 year with 28.0 cases per 100'000 and lowest in 9 year olds with 9.0 cases per 100'000 (Figure 6 shows the crude incidence rates and Figure 7 shows age- and gender-specific incidence rates).

[4] Parkin DM, Kramarova E, Draper GJ, Masuyer E, Michaelis J, Neglia J, et al. The international incidence of childhood cancer, Vol II. Lyon: IARC Scientific Publications; 1998.

Table 1 Registered cases in the SCCR according to country of residence

Country of residence	Number of cases	% of total cases
1 Switzerland	4406	87.9
2 Other countries	481	9.6
a Europe	335	6.7
Neighbouring countries*	207	4.1
Other European countries	128	2.6
b Middle East	10	0.2
c North Africa	77	1.5
d Other African countries	35	0.7
e Other countries	21	0.4
3 Country of residence missing	127	2.5
Before 1990	120	94.5
After 1990	7	5.5
Total Cases	5014	100

* Austria (N=7), France (N=51), Germany (N=43), Italy (N=97), Lichtenstein (N=9)

Table 2 Number of new cases registered in the SCCR, for 5-year intervals

Year of Diagnosis	All patients	Swiss residents
until 1980	485	418
1981-1985	658	565
1986-1990	779	631
1991-1995	982	856
1996-2000	1022	919
2001-2005	1088	1017

Figure 1 Number of new patients registered each year in the SCCR

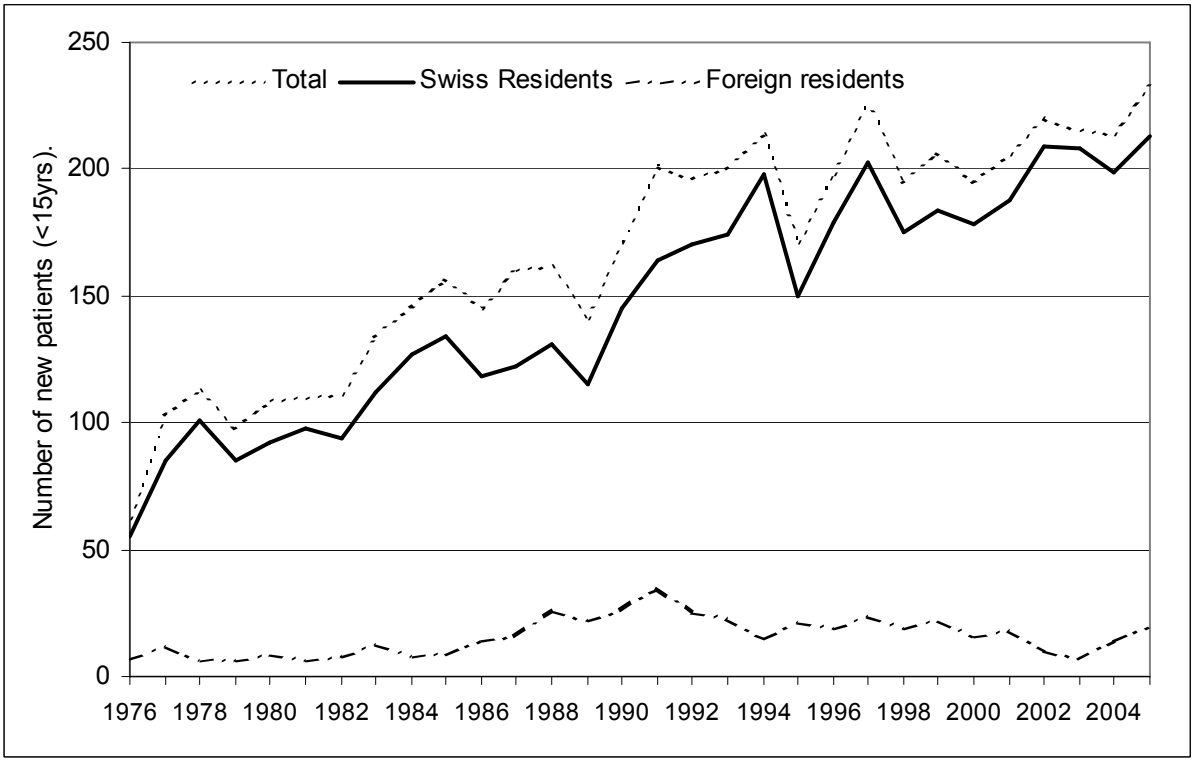


Table 3 Number of patients in the SCCR database (Swiss residents aged under 15 years)

	Number of patients	%
Died	1006	24.4
Last follow-up after 31 Dec 2002	1434	34.8
Last follow-up 2000-2002	141	3.4
Last follow-up before 1 Jan 2000	509	12.3
Lost to follow-up	681	16.5
no Information	351	8.5
Total until December 31 2005	4122	100.0

Table 4 Age at diagnosis (Swiss residents aged under 15 years)

Age in years	Number of patients	%
< 1	430	10.4
1 – 4	1508	36.6
5 – 9	1113	27.0
10 – 14	1071	26.0
Total <15 years	4122	100.0

Figure 2 Age at diagnosis (Swiss residents aged under 15 years diagnosed between 1 Jan 1976 and 31 Dec 2005)

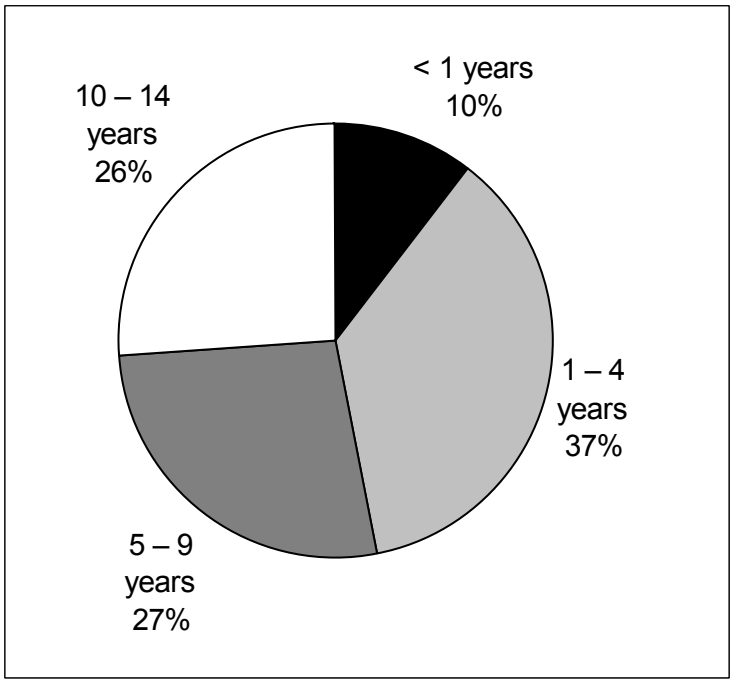


Figure 3 Age at diagnosis (Swiss residents aged under 15 years, N=4122)

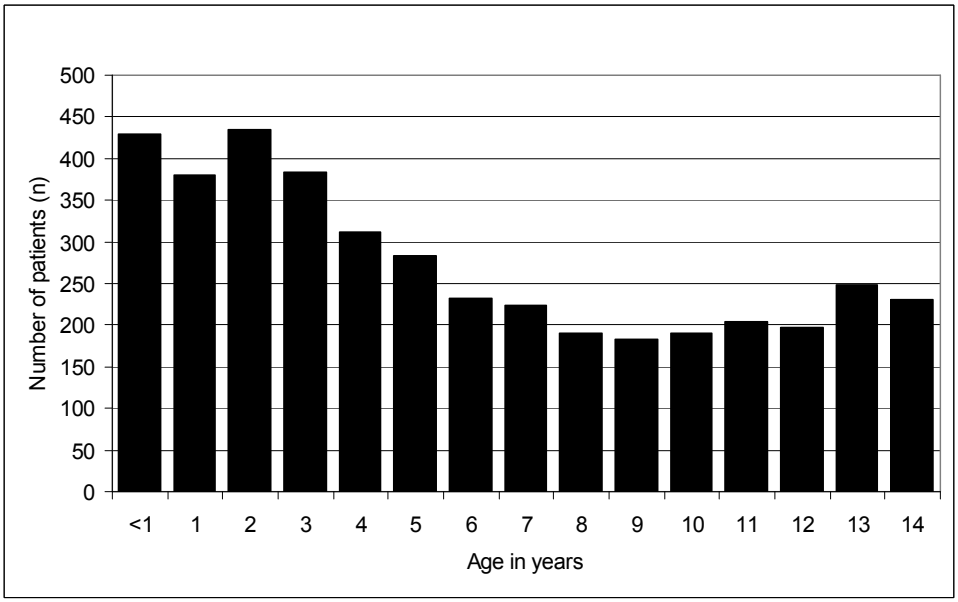


Figure 4 Age at diagnosis, by sex (Swiss residents aged under 15 years, N=4122)

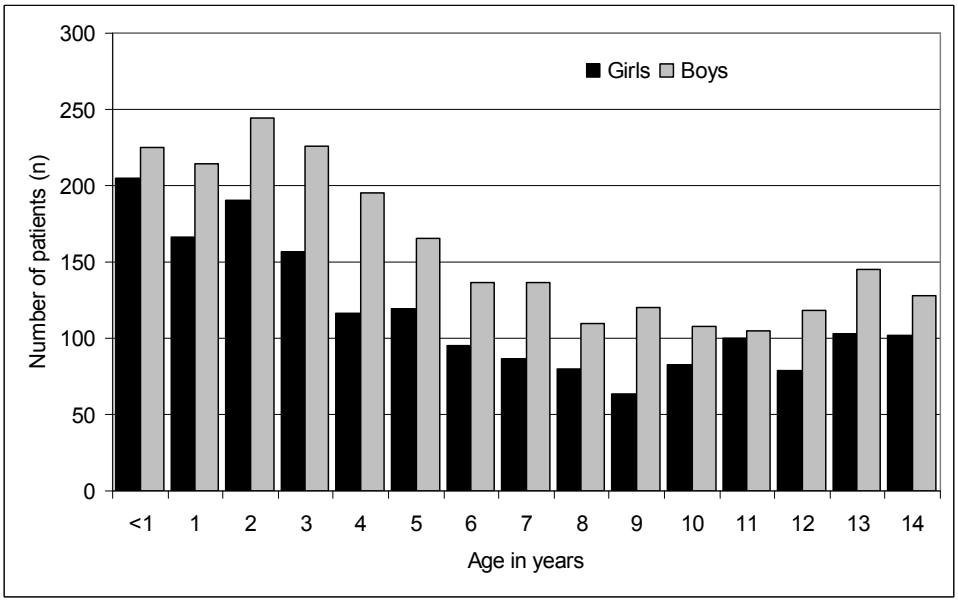


Table 5 Details on diagnostic group according to ICCC-3 (Swiss residents aged under 15 years diagnosed between 1 Jan 1976 and 31 Dec 2005)

		Total	Age group			
	Diagnosis	**number**	**<1yr**	**1-4yrs**	**5-9yrs**	**10-14yrs**
I	Leukaemias	1461	52	705	417	287
II	Lymphomas	561	16	87	163	295
III	CNS neoplasms	708	55	215	262	176
IV	Neuroblastoma	275	123	117	23	12
V	Retinoblastoma	113	54	49	8	2
VI	Renal tumours	234	36	137	53	8
VII	Hepatic tumours	40	11	15	5	9
VIII	Malignant bone tumours	172	0	14	53	105
IX	Soft tissue sarcomas	245	29	75	67	74
X	Germ cell tumours	103	18	25	14	46
XI	Carcinomas	46	3	5	8	30
XII	Other and unspecified malignant neoplasms	6	0	3	1	2
	Langerhans Cell Histiocytosis	158	33	61	39	25
	Total	**4122**	**430**	**1508**	**1113**	**1071**

Figure 5 Distribution of diagnoses according to ICCC-3 (Swiss residents aged under 15 years diagnosed between 1 Jan 1976 and 31 Dec 2005)

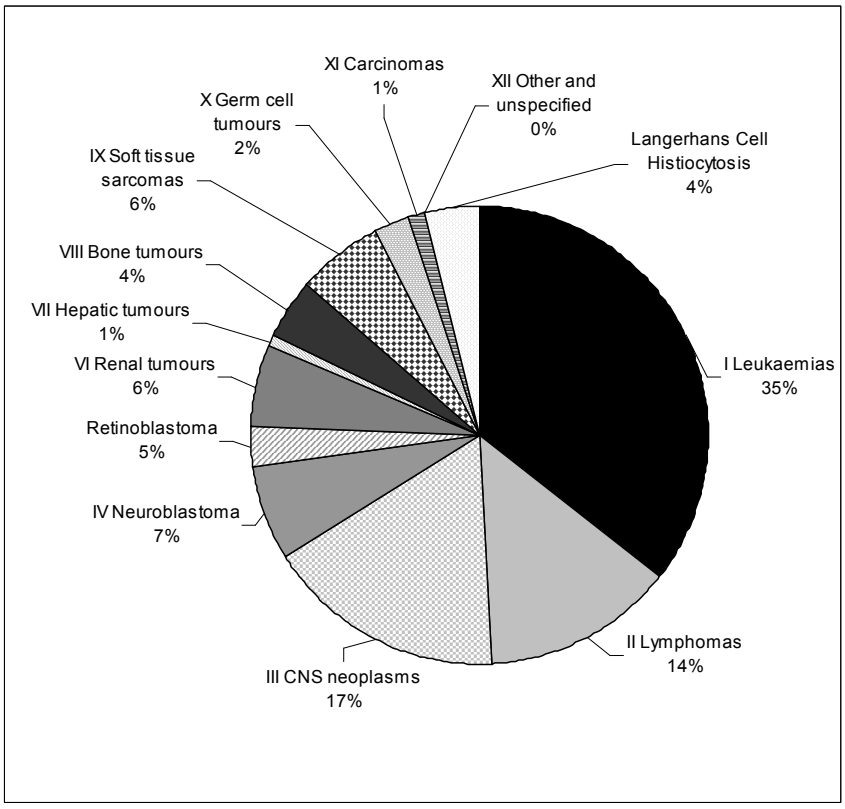


Table 6 Diagnosis according to ICCC-3 in Swiss patients aged under 15 years diagnosed between 1996 and 2005

		Number	Relative Frequency	Sex Ratio (male: female)	Mean age	Incidence (per 1Mio)
I	**Leukaemias, myeloproliferative diseases, and myelodysplastic diseases**	**562**	**32.5**	**1.4**	**4.8**	**45.7**
	a. Lymphoid leukaemias	448	79.7	1.4	4.7	36.4
	b. Acute myeloid leukaemias	83	14.8	1.2	5.4	6.7
	c. Chronic myeloproliferative diseases	5	0.9	1.5	9.5	0.4
	d. Myelodysplastic syndrome and other myeloproliferative diseases	18	3.2	1.0	8.5	1.5
	e. Unspecified and other specified leukaemias	8	1.4	3.0	5.3	0.7
II	**Lymphomas and reticuloendothelial neoplasms**	**211**	**12.2**	**1.8**	**10.6**	**17.2**
	a. Hodgkin lymphomas	80	37.9	1.3	12.8	6.5
	b. Non-Hodgkin lymphomas (except Burkitt)	101	47.9	2.1	9.0	8.2
	c. Burkitt lymphoma	25	11.8	4.0	8.5	2.0
	d. Miscellaneous lymphoreticular neoplasms	4	1.9	3.0	0.9	0.3
	e. Unspecified lymphomas	1	0.5	0.0	13.6	0.1
III	**CNS and miscellaneous intracranial and intraspinal neoplasms**	**397**	**23.0**	**1.2**	**6.3**	**32.3**
	a. Ependymomas and choroid plexus tumours	40	10.1	1.4	2.1	3.3
	b. Astrocytomas	146	36.8	1.2	6.6	11.9
	c. Intracranial and intraspinal embryonal tumours	105	26.4	1.9	5.8	8.5
	d. Other gliomas	41	10.3	0.8	6.4	3.3
	e. Other specified intracranial and intraspinal neoplasms	61	15.4	0.8	10.1	5.0
	f. Unspecified intracranial and intraspinal tumours	4	1.0	1.0	11.9	0.3
V	**Neuroblastomas and other peripheral nervous cell tumours**	**101**	**5.8**	**0.9**	**1.0**	**8.2**
	a. Neuroblastoma and ganglioneuroblastoma	101	100.0	0.9	1.0	8.2
V	**Retinoblastomas**	**51**	**2.9**	**1.0**	**0.8**	**4.1**
VI	**Renal Tumours: Nephroblastoma and other nonepithelial tumours**	**96**	**5.6**	**1.0**	**3.3**	**7.8**
	a. Nephroblastoma and other nonepithelial renal tumours	95	99.0	1.1	3.2	7.7
	b. Renal carcinomas	1	1.0	0.0	14.7	0.1
VII	**Hepatic tumours**	**27**	**1.6**	**3.5**	**1.6**	**2.2**
	a. Hepatoblastomas	20	74.1	5.7	1.2	1.6
	b. Hepatic carcinomas	7	25.9	1.3	13.4	0.6
VIII	**Malignant bone tumours**	**90**	**5.0**	**1.0**	**11.0**	**7.3**
	a. Osteosarcomas	47	52.2	0.7	10.8	3.8
	c. Ewing tumour and related sarcomas of bone	43	47.8	1.3	11.0	3.5
IX	**Soft tissue and other extraosseous sarcomas**	**115**	**6.7**	**1.4**	**6.6**	**9.3**
	a. Rhabdomyosarcomas	73	63.5	2.0	5.0	5.9
	b. Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	9	7.8	2.0	1.1	0.7
	d. Other specified soft tissue sarcomas	21	18.3	0.8	11.3	1.7
	e. Unspecified soft tissue sarcomas	12	10.4	0.3	9.7	1.0
X	**Germ cell tumours, trophoblastic tumours, and neoplasms of gonads**	**50**	**2.9**	**0.8**	**8.2**	**4.1**
	a. Intracranial and intraspinal germ cell tumours	14	28.0	2.5	10.9	1.1
	b. Malignant extracranial and extragonadal tumours	12	24.0	0.2	1.3	1.0
	c. Malignant gonadal germ cell tumours	23	46.0	0.8	10.1	1.9
	d. Gonadal carcinomas	1	2.0	0.0	13.9	0.1
XI	**Other malignant epithelial neoplasms and malignant melanomas**	**28**	**1.6**	**0.9**	**11.7**	**2.3**
	a. Adrenocortical carcinomas	4	14.3	0.3	8.4	0.3
	b. Thyroid carcinomas	13	46.4	0.9	12.7	1.1
	d. Malignant melanomas	6	21.4	1.0	11.5	0.5
	e. Skin carcinomas	1	3.6		2.6	0.1
	f. Other and unspecified carcinomas	4	14.3	1.0	11.0	0.3
XII	**Other and unspecified malignant neoplasms**	**1**	**0.1**		**12.9**	**0.1**
	b. Other unspecified malignant tumours	1	100.0		12.9	0.1
	Total (not including Langerhans Cell Histiocytosis)	**1729**	**100.0**	**1.3**	**6.0**	**140.5**
	Langerhans Cell Histiocytosis	63	3.5	1.5	3.7	5.1
	Total (including Langerhans Cell Histiocytosis)	1792	100.0	1.3	6.4	145.7

Table 7 Diagnosed childhood cancer cases*, by participating paediatric oncology clinic (total database 1976-1995)**

	Diagnosis	Total	%	Aarau	%	Basel	%	Bern	%	Geneva	%	Lausanne	%	Locarno	%	Lucerne	%	St. Gallen	%	Zurich	%	Other	%
I	Leukaemias	1022	100	72	7.0	102	10.0	281	27.5	88	8.6	98	9.6	16	1.6	79	7.7	107	10.5	176	17.2	3	0.3
II	Lymphomas	424	100	29	6.8	44	10.4	103	24.3	37	8.7	61	14.4	7	1.7	25	5.9	37	8.7	80	18.9	1	0.2
III	CNS neoplasms	395	100	25	6.3	31	7.8	147	37.2	29	7.3	49	12.4	8	2.0	8	2.0	34	8.6	64	16.2	0	0.0
IV	Neuroblastoma	211	100	7	3.3	20	9.5	40	19.0	21	10.0	38	18.0	0	0.0	15	7.1	18	8.5	51	24.2	1	0.5
V	Retinoblastoma***	141	100	0	0.0	6	4.3	16	11.3	15	10.6	81	57.4	2	1.4	6	4.3	8	5.7	7	5.0	0	0.0
VI	Renal tumours	159	100	5	3.1	14	8.8	36	22.6	10	6.3	20	12.6	0	0.0	17	10.7	15	9.4	41	25.8	1	0.6
VII	Hepatic tumours	19	100	0	0.0	1	5.3	9	47.4	2	10.5	2	10.5	0	0.0	0	0.0	0	0.0	5	26.3	0	0.0
VIII	Malignant bone tumours	154	100	5	3.2	23	14.9	47	30.5	19	12.3	29	18.8	2	1.3	6	3.9	10	6.5	12	7.8	1	0.6
IX	Soft tissue sarcomas	169	100	6	3.6	16	9.5	45	26.6	11	6.5	29	17.2	3	1.8	13	7.7	19	11.2	27	16.0	0	0.0
X	Germ cell tumours	78	100	6	7.7	7	9.0	18	23.1	7	9.0	12	15.4	2	2.6	2	2.6	4	5.1	20	25.6	0	0.0
XI	Carcinomas	24	100	1	4.2	1	4.2	6	25.0	4	16.7	6	25.0	1	4.2	1	4.2	1	4.2	3	12.5	0	0.0
XII	Other and unspecified malignant neoplasms	7	100	0	0.0	1	14.3	2	28.6	0	0.0	3	42.9	0	0.0	0	0.0	0	0.0	1	14.3	0	0.0
	Langerhans Cell Histiocytosis	101	100	4	4.0	14	13.9	24	23.8	4	4.0	11	10.9	1	1.0	6	5.9	19	18.8	18	17.8	0	0.0
	Total	2904	100	160	5.5	280	9.6	774	26.7	247	8.5	439	15.1	42	1.4	178	6.1	272	9.4	505	17.4	7	0.2

* Diagnosis coded according to the ICCC-3

** All patients irrespective of age and residency (Swiss and foreign patients) are included in this analysis

*** Most cases with retinoblastoma are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne

Table 8 Diagnosed childhood cancer cases*, by participating paediatric oncology clinic (patients diagnosed between 1996 and 2005)**

	Diagnosis	Total	%	Aarau	%	Basel	%	Bern	%	Geneva	%	Lausanne	%	Locarno	%	Lucerne	%	St. Gallen	%	Zurich	%	Other	%
I	Leukaemias	633	100	44	7.0	52	8.2	109	17.2	49	7.7	90	14.2	17	2.7	45	7.1	64	10.1	163	25.8	0	0.0
II	Lymphomas	264	100	16	6.1	16	6.1	49	18.6	21	8.0	44	16.7	9	3.4	29	11.0	23	8.7	57	21.6	0	0.0
III	CNS neoplasms	437	100	23	5.3	26	5.9	98	22.4	45	10.3	72	16.5	14	3.2	4	0.9	37	8.5	118	27.0	0	0.0
IV	Neuroblastoma	112	100	4	3.6	13	11.6	16	14.3	9	8.0	20	17.9	1	0.9	9	8.0	9	8.0	31	27.7	0	0.0
V	Retinoblastoma***	113	100	0	0.0	5	4.4	4	3.5	3	2.7	88	78.8	1	0.0	3	2.7	3	2.7	6	5.3	0	0.0
VI	Renal tumours	104	100	7	6.7	11	10.6	19	18.3	14	13.5	13	12.5	4	3.8	5	4.8	9	8.7	22	21.2	0	0.0
VII	Hepatic tumours	30	100	4	13.3	3	10.0	4	13.3	1	3.3	5	16.7	2	6.7	0	0.0	4	13.3	7	23.3	0	0.0
VIII	Malignant bone tumours	125	100	6	4.8	24	19.2	22	17.6	17	13.6	21	16.8	2	1.6	3	2.4	10	8.0	20	16.0	0	0.0
IX	Soft tissue sarcomas	130	100	12	9.2	12	9.2	20	15.4	9	6.9	22	16.9	1	0.8	13	10.0	10	7.7	31	23.8	0	0.0
X	Germ cell tumours	59	100	7	11.9	2	3.4	9	15.3	7	11.9	11	18.6	1	1.7	5	8.5	5	8.5	11	18.6	1	1.7
XI	Carcinomas	35	100	3	8.6	5	14.3	8	22.9	2	5.7	3	8.6	1	2.9	3	8.6	4	11.4	6	17.1	0	0.0
XII	Other and unspecified malignant neoplasms	1	100	0	0.0	0	0.0	0	0.0	1	100.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
	Langerhans Cell Histiocytosis	65	100	5	7.7	4	6.2	17	26.2	2	3.1	12	18.5	3	4.6	4	6.2	5	7.7	13	20.0	0	0.0
	Total	2108	100	131	6.2	173	8.2	375	17.8	180	8.5	401	19.1	56	2.6	123	5.8	183	8.7	485	23.0	1	0.0

* Diagnosis coded according to the ICCC-3

** All patients irrespective of age and residency (Swiss and foreign patients) are included in this analysis

*** Most cases with retinoblastoma are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne

Table 9 Diagnosed childhood cancer cases*, by participating paediatric oncology clinic (new patients diagnosed in 2005)**

	Diagnosis	Total	Aarau	Basel	Bern	Geneva	Lausanne	Locarno	Lucerne	St. Gallen	Zurich
I	Leukaemias	70	4	5	10	6	8	1	7	8	21
II	Lymphomas	34	1	3	7	2	5	0	3	6	7
III	CNS neoplasms	55	1	2	10	2	8	1	1	3	27
IV	Neuroblastoma	7	0	0	1	0	1	0	3	0	2
V	Retinoblastoma***	14	0	0	1	0	10	1	1	1	0
VI	Renal tumours	11	2	0	1	1	2	0	0	2	3
VII	Hepatic tumours										
VIII	Malignant bone tumours	15	0	8	0	0	4	0	0	0	3
IX	Soft tissue sarcomas	15	2	5	2	1	0	0	0	1	4
X	Germ cell tumours	3	0	0	0	0	1	0	2	0	0
XI	Carcinomas	3	0	0	0	0	0	0	1	0	2
XII	Other and unspecified malignant neoplasms										
	Langerhans Cell Histiocytosis	6	1	0	2	0	1	0	1	0	1
	Total	233	11	23	34	12	40	3	19	21	70

* Diagnosis coded according to the ICCC-3

** All patients irrespective of age and residency (Swiss and foreign patients) are included in this analysis

*** Most cases with retinoblastoma are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne

Figure 6 Crude incidence rates in Switzerland for all malignancies between 1990 and 2005 for children aged 0-14 years (not including Langerhans cell histiocytosis)

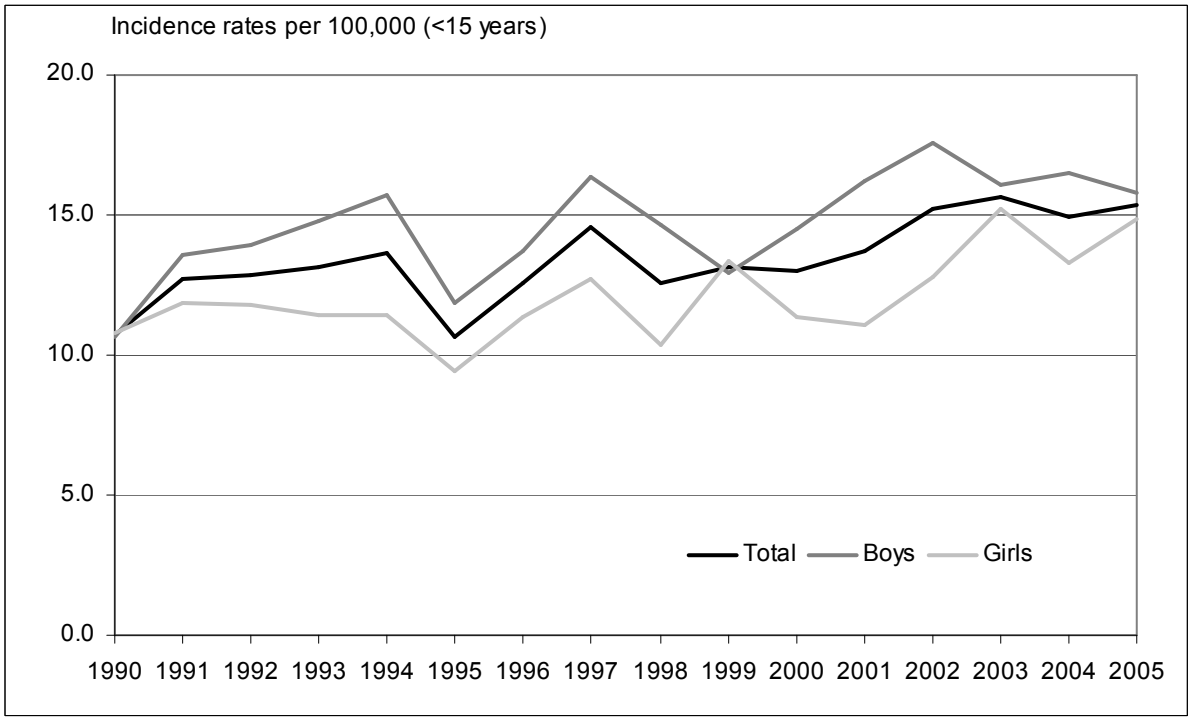
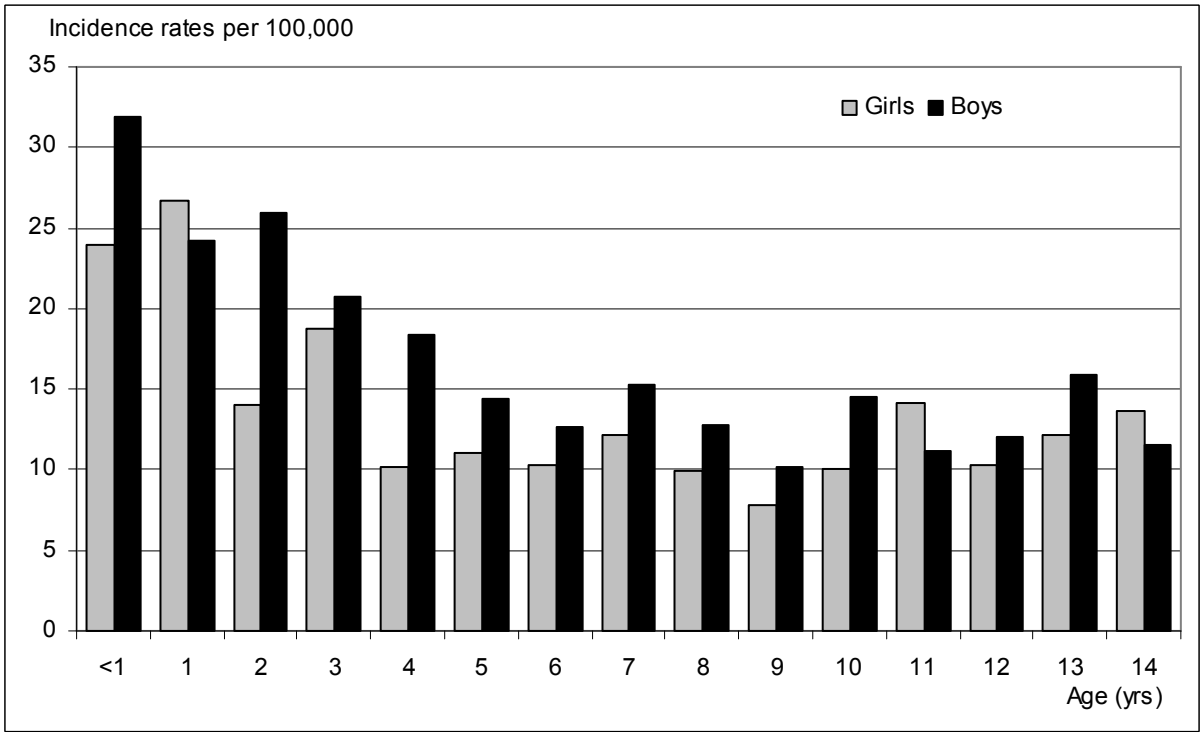


Figure 7 Age- and sex-specific incidence rates (Switzerland 2001-2005, not including Langerhans cell histiocytosis)



4 Current research projects at the SCCR

4.1 Collaboration with SPOG studies (data-extraction or analysis)

We extracted data or performed analyses for studies conducted by different SPOG clinics.

1. Title: **Survival of childhood cancer in the past 30 years in Zurich**
Applicant: Prof. Dr. med. F. Niggli
Population: 655 children with cancer treated in Zurich for whom follow-up information is available. 167 of these patients were registered as having died

2. Title: **Retinoblastoma treatment in Switzerland**
Supervisor Dr. med. F. M. Beck Popovic
Student: M. Wallach
Population: In August 2005, there were 245 patients with retinoblastomas registered in the SCCR. 161 of these patients were treated in Lausanne and 84 in other clinics
Data extracted: Year of diagnosis, treating institutions
Publications: Wallach, M., Balmer, A., Munier, F., Houghton, S., Pampallona, S., von der Weid, N., et al. (2006). Shorter time to diagnosis and improved stage at presentation in Swiss patients with retinoblastoma treated from 1963 to 2004. Pediatrics, 118(5), e1493-1498. DOI:10.1542/peds.2006-0784

3. Title: **Renal tumours in Switzerland**
Supervisor Dr. med. M. Diezi
Extraction: From 1992 to 2004, the SCCR registered 145 patients with renal tumours. 8 of these patients are not Swiss residents but only came here for treatment. The average annual number of new cases was 11.2 from 1992 to 2004. The mean age of the children at diagnoses was 3.5.
Publications: Diezi M, Tercier S, Osterheld M-C, Joseph J-M, Tumeurs rénales de l'enfant. Revue Médicale Suisse 2007;3:360-5

4. Title: **Childhood acute myeloid leukaemia: the clinical significance of cytogenetic events at presentation and relapse**
Supervisor Dr. D. Betts
Population: For 99 of the 103 patients tumour and therapy details were extracted from the SCCR.
Data extracted: Date of 1st Diagnosis, Date 2nd Diagnosis, Date 3rd Diagnosis, Date 1st relapse, Date 2nd relapse, Date 3rd relapse, Date last seen, Date lost to follow-up, Date exitus, Bone marrow transplantation (1 yes/0 no), Date bone marrow transplantation, bone marrow transplantation type, code bone marrow transplantation, prior Disease (1 yes/ 0 no), description of prior disease, survival time, event-free survival time
Publications: under review

5. Title: **Wilm's Tumour, Soft Tissue Sarcoma and autologous bone marrow transplantation**
Supervisor PD Dr. med. N. von der Weid
Population: For the years 2000 to 2005, data on 3 patients with either Wilm's Tumour or Soft Tissue Sarcoma and an autologous bone marrow transplantation were extracted
Data extracted: Diagnosis, year of diagnosis, autologous bone marrow transplantation

6. Title: **Number of patients with Ewing-Sarcomas or Rhabdomyosarcomas**
Supervisor Prof. Dr. med. M. Paulussen
Population: For the years 2000 to 2004, 32 patients with Rhabdomyosarcoma, 23 with Ewing-Sarcomas, 7 with extra-osseus Ewing-Sarcomas and 3 with a rhabdoid malignancy were extracted.
Data extracted: Diagnosis, year of diagnosis

7. Title: **Leukaemia in Switzerland**
Supervisor Dr. J.-P. Bourquin
Population: Leukaemia cases in Switzerland since 1994 by sex.
Data extracted: Diagnosis, year of diagnosis, gender

8. Title: **Craniopharyngeoma patients in Bern**
Supervisor Dr. M. Janner
Population: all patients diagnosed with a craniopharyngeoma in Bern (N=17)
Data extracted: First name, family name, date of birth, date of diagnosis, gender

4.2 SCCR research projects

In 2005 and 2006, four research projects started as nested studies of the SCCR.

4.2.1 Long-term outcome of childhood cancer: incidence and spectrum of late effects

Aims: The Swiss Childhood Cancer Survivor Study of the SCCR aims to investigate the long-term outcome of former childhood cancer patients who were diagnosed with cancer before the age of 16 years and who survived for more than 5 years. The project aims to assess the incidence of various somatic outcomes (late mortality, secondary malignancies, endocrine disorders, infertility, cardiovascular events), and their association with a number of risk factors assessed prospectively at the time of diagnosis (tumour, treatment modalities, demographic characteristics). In addition, the current practice of health-care provision and health behaviour in long-term survivors will be investigated.

Study progress: In 2006, the questionnaire for the study was developed and 100 survivors from Bern and Zurich (50 from each clinic) were contacted by means of a letter from their former clinic and invited to participate in the study. None of the survivors who received the letter declined to participate in the study. They received the questionnaire 3 weeks after the first contact.

By the end of 2007 all survivors should have received the questionnaire. Separate questionnaires are used for adults older than 20 years, adolescents older than 14 years and children (parents are asked to fill in the questionnaire and only a short questionnaire assessing quality of life is filled in by the children themselves). Questionnaires are available in German and French.

Collaborators: The research proposal is a collaborative project of the SPOG (PD Dr. Nicolas von der Weid, Main Investigator), the ISPM Bern (Prof. Dr. Matthias Egger, Dr. Claudia Kuehni, Co-applicants) and the cantonal registries (PD Dr. Nicole Probst-Hensch, Co-applicant).

Members of the late effects study group:

Dr. med. Claudia Kuehni, Dr. phil. Gisela Michel, PD Dr. med. Nicolas von der Weid, Dr. phil. Marcel Zwahlen, Prof. Dr. med. Felix Niggli, PD Dr. med. Michael Grotzer

PhD-Student: Fabienne Zurbriggen was working in the project from 1 January – 31 July 2006. On 1 October 2006, Cornelia E. Rebholz started as a PhD student.

Duration: The study began on 1st January 2006 and will be funded for 3 years.

Funding Office: Oncosuisse (265 900 CHF)

Abstracts:

Rebholz, C.E., Michel, G., von der Weid, N., & Kuehni, C.E (January, 2007). The Swiss Childhood Cancer Survivor Study : an update. Annual meeting of the Swiss Paediatric Oncology Group (SPOG), Locarno, CH

Zurbriggen, F., von der Weid, N., Michel, G. & Kuehni, C.E (February, 2006). Late effects in childhood cancer survivors: Aims and methods of the new study. Annual meeting of the Swiss Paediatric Oncology Group (SPOG), Locarno, CH.

4.2.2 Health related quality of life and health behaviour in childhood cancer survivors

This study is an add-on project to the late effects study funded by Oncosuisse, and is funded by the Wyeth foundation.

Aims: 1) To determine in long-term survivors of childhood cancer in Switzerland: a) health related quality of life (HRQoL), and the prevalence of risk behaviours (smoking, alcohol), information about physical activity, diet and body weight, and b) to compare these findings to existing data from general population samples in Switzerland.

2) To study associations between current HRQoL and health behaviour in survivors with prospectively collected data on risk factors, including socio-demographic and clinical determinants at the time of diagnosis, treatment modalities and relapses. This will allow us to define groups of children at increased risk for detrimental effects and behaviours, who might profit from specific interventions.

For an update on the project status see 4.2.1.

Collaborators: The research proposal is a collaborative project of the ISPM Bern (Dr. Claudia Kuehni, Main Investigator, Dr. Gisela Michel, Prof. Dr. Matthias Egger, Co-applicants) and of the SPOG (PD Dr. Nicolas von der Weid, Co-applicant).

PhD-Student: Fabienne Zurbriggen was working in the project from 1 January – 31 July 2006. On 1 October 2006, Cornelia E. Rebholz started as a PhD student.

Duration: The study began on 1 January 2006 and is funded for 1.5 years.

Funding Office: Wyeth Foundation (30 088 CHF)

4.2.3 Completeness of cancer registration and diagnostic accuracy in the Swiss Childhood Cancer Registry: validation against independent sources of data

Aims: The research project aims to validate and complete records of the SCCR against independent sources of data from cantonal registries of the Association of Swiss Cancer Registries (VSKR). A standardised protocol for regular future cross-validation between these databases is being developed.

Until the end of 2006 the linkage was completed for 8 of the 9 cantonal registries. Detailed analyses are being done until end of July 2007.

Collaborators: Prof. Dr. Matthias Egger (Main Investigator, ISPM), Dr. Claudia Kuehni (Co-Applicant, ISPM), Dr. Silvia Ess (Co-applicant VSKR) and PD Dr. med. Nicolas von der Weid (Co-Applicant, SPOG).

PhD-Student: Martin Adam started as a PhD student in the project on 1 Mai 2006.

Duration: The study started on 1st Mai 2006 and is funded for 15 months

Funding Office: Bernische Krebsliga (Cancer League of Bern, 80 000 CHF)

Abstract:

Michel, G., Adam, M., von der Weid, N., & Kuehni, C.E (January, 2007). Comparing SCCR with Cantonal cancer registries: Is our database complete? Annual meeting of the Swiss Paediatric Oncology Group (SPOG), Locarno, CH

4.2.4 Cefalo: An international case-control study on brain tumours in children and adolescents

Aims: The main goal of the study is to investigate whether the use of mobile telephones increases the risk of developing brain tumours for children or adolescents. In addition, the study will provide a comprehensive dataset to investigate other potential risk factors for childhood brain tumour. The questions under study will be investigated by means of a case-control study in Denmark, Norway, Sweden and Switzerland.

Study progress: Until the end of 2006, 68 eligible families were invited to participate in the study in Switzerland. A total of 43 interviews were completed (including 22 cases). Six families refused to participate (3 cases, 3 controls), 2 families agreed to fill in a written questionnaire only, and 17 families have not responded yet.

Collaborators: Dr. Martin Röösli (Head of the Environmental Health Research Group, ISPM Bern), Dr. Claudia E Kuehni (Head of the Swiss Childhood Cancer Registry), PD Dr. Michael Grotzer (Head of Paediatric Neuro-Oncology, Zurich), PD Dr. Nicolas von der Weid (Head of the Swiss Paediatric Oncology Group), Dr. Joachim Schüz (Head of department, Institute of Cancer Epidemiology, Copenhagen, Denmark), Dr. Maria Feychting (Professor, Karolinska Institute, Stockholm, Sweden) and Dr. Tore Tynes (Cancer Registry of Norway, Oslo, Norway)

Research assistant: Daniela Jenni started in the project on 1 January 2006.

Duration: The study started on 1 January 2006 and will be funded for 3 years

Funding Office: Forschungsstiftung Mobilfunk Schweiz (310 000 CHF), Bundesamt für Gesundheit (149 600 CHF)

Abstract:

Röösli M., for the Cefalo Study Group. An international case-control study on mobile phone use and the risk of brain tumours in children and adolescents (Cefalo study): study design and first experiences from the field work. Scientific Workshop hosted by the FGF: Do Children Represent a Special Sensitive Group for EMF-Exposure? - State of Research. Stuttgart, 27-29 November 2006. (www.cost281.org)

Schüz J, Feychting, M., Röösli M., Tynes T., Samsø Schmidt L., Johansen C., Prohazka M., Sverin E., Jenni D., Kuehni C., Klaboe L. An international case-control study on mobile phone use and the risk of brain tumours in children and adolescents (Cefalo study): a report from the field work and first results on mobile phone usage among children. 8th International Congress of the European Bioelectromagnetics Association (EBEA), Bordeaux 10-13 April 2007.

4.2.5 Childhood leukaemia and lymphoma: are incidence and survival in Switzerland associated with socioeconomic status?

Inequalities in health between socio-economic groups are a major public health concern. Numerous epidemiological studies have found higher rates of total mortality and morbidity among infants, children and adults with a lower socio-economic status (SES), defined on an individual or area-level. For childhood cancer, and its most common diagnostic group, childhood leukaemia, the available data are contradictory. Some publications suggested that acute lymphoblastic leukaemia was more common in children of high SES. However, more recent studies reported associations in the opposite direction. Infections have been implicated in the aetiology of lymphomas, which could, in turn, be reflected in SES differentials in lymphoma risk. The Swiss setting provides an ideal opportunity to study these questions.

Aims: The research project aims to investigate the association of socio-economic status with the risk of developing childhood leukaemia or childhood lymphoma, and to explore whether the association is varying with the operational definition of socio-economic status. In addition, we aim to investigate the association of socio-economic status with the five-year survival rate for cases of childhood leukaemia or childhood lymphoma.

Collaborators: Dr. Marcel Zwahlen (Main Investigator, ISPM), Prof. Dr. Matthias Egger and Dr. Claudia Kuehni (Co-Applicants, ISPM), and PD Dr. med. Nicolas von der Weid (Co-Applicant, SPOG).

PhD-Student: Martin Adam is managing the project as PhD student.

Duration: The study started on 1 January 2007 and is funded for 2 years.

Funding Office: Oncosuisse (171 400 CHF)

4.2.6 Validating date and cause of death information in the Swiss Childhood Cancer Registry against death certificate information from the Swiss Federal Office of Statistics

Aims: To validate SFSO death certificate information and to update information on vital status in the SCCR using an independent information source.

Method: The Swiss Childhood Cancer Registry (SCCR) patients were linked to information from official death certificates recorded by the SFSO using probabilistic record linkage procedures.

Results: The project validating mortality in the SCCR and mortality statistics of the SFSO showed that procedures for probabilistic record linkage could be used to link the SCCR and SFSO datasets and that for a major part (80%) of patients recorded as having died in the SCCR a perfectly linked record from the SFSO could be found.

Comparison of the cause of death of the linked records in both databases showed that for the large majority of individuals, the cause of death was similar in both datasets. Ninety-three percent of records coded according to ICD-8 and 85% of records coded according to ICD-10 (by the SFSO) had either both recorded cancer or both recorded something other than cancer as cause of death. The agreement between the diagnoses of cancer in the SCCR and the cause of death in the SFSO was particularly high for leukaemia.

Comparison of the agreement between the cause of death in both databases showed that the strongest predictor was the coding system used by the SFSO, with the period since 1995 (ICD-10) showing poorer agreement compared to the period before, when diagnoses were coded according to ICD-8. In addition to changing the classification system, the coding procedures at the SFSO were also changed between these two periods, from internal SFSO prioritising rules (for ICD-8) to the prioritising rules published by the WHO (for ICD-10). These changes may be related to the deterioration of the

agreement between the causes of deaths recorded in the SCCR and the SFSO. Within those two time periods, there was no significant change of agreement by calendar years.

Collaborators: Dr. Claudia Kuehni (Main Investigator, ISPM), Dr. Marcel Zwahlen, Prof. Dr. Matthias Egger (Co-Applicants, ISPM), and PD Dr. med. Nicolas von der Weid (Co-Applicant, SPOG). The linkage was done by Malcolm Sturdy, the analysis and writing up by Gisela Michel, Marie-Pierre Strippoli and Claudia Kuehni.

Duration: The study was finished at the end of 2005.

Funding Office: Swiss Federal Statistical Office (SFSO, 20 000 CHF)

Publications/Reports:

Michel G, Sturdy M, Zwahlen M, Strippoli M-PF, von der Weid N, Kuehni CE. Validating date and cause of death information in the Swiss Childhood Cancer Registry against death certificate information from the Swiss Federal Office of Statistics (1976-2004). Bern: Institute of Social and Preventive Medicine, University of Bern, 2006.

Michel, G., Zwahlen, M & Kuehni, C. Linkage of mortality data for the Swiss childhood cancer registry and the Swiss mortality statistics, in preparation.

5 Review of activities 2005/2006

5.1 Reports and Publications

The Swiss Childhood Cancer Registry submitted three papers to scientific Journals in 2006:

- Michel G, von der Weid NX, Zwahlen M, Redmond S, Strippoli MP, Kuehni CE. Incidence of childhood cancer in Switzerland: The Swiss childhood cancer registry. Pediatric Blood & Cancer 2007;DOI 10.1002/pbc.21129.
- Roosli M, Michel G, Kuehni CE, Spoerry A. Cellular telephone use and time trends in brain tumour mortality in Switzerland from 1969 to 2002. European Journal of Cancer Prevention 2007;16(1):77-82.
- Michel G, von der Weid NX, Zwahlen M, Adam M, Rebholz CE, Kuehni C. The Swiss Childhood Cancer Registry: rationale, organisation and results for the years 2001-2005. under review

The linkage of the SCCR data with the mortality statistics of the Swiss Federal Statistical Office (SFSO) was repeated including the year 2004. A report is available from the SCCR:

- Michel G, Sturdy M, Zwahlen M, Strippoli M-PF, von der Weid N, Kuehni CE. Validating date and cause of death information in the Swiss Childhood Cancer Registry against death certificate information from the Swiss Federal Office of Statistics (1976-2004). Bern: Institute of Social and Preventive Medicine, University of Bern, 2006.

5.2 Concept for the planned database renewal

The current SCCR database was implemented in 1992 using the Microsoft Access 2.0 relational database system running on a self-contained Windows desktop PC. New requirements on the SCCR database, mainly in the areas of data security / privacy and data model, provided the opportunity to analyse the current situation, develop a replacement SCCR database concept and implement the result.

The new database concept includes various improvements:

- Strict separation of personal data from all other disease relevant information
- Keeping history of data changes (such as changes of address, names etc.)
- SQL database server
- ACCESS front end

In 2005 and 2006 the data have been migrated from the old database to the new data structure. The database is currently under construction and will be finalised by June 2007. A detailed description will be included in the next Annual Report.

5.3 Funding of the SCCR

The SCCR thanks the following sponsors for their generous unrestricted financial support:

Since 2004

Swiss Paediatric Oncology Group

2006-2008

Novartis

Winterthur

2007

GlaxoSmithKline

Kinderkrebshilfe Schweiz

Amgen

Stiftung zur Förderung von sozialen Massnahmen
in der Kranken- und Unfallversicherung

2006

Bristol-Myers Squibb

Interpharma

Baxter

2005

Valiant Bank

5.4 General registry work

5.4.1 Recoding of Diagnoses

Until 2004, all tumours were coded according to the coding used by the American Paediatric Oncology Group (POG). In 2005 and 2006 all tumours registered in the SCCR have been retrospectively coded according to:

- The third revision of the International Classification of Childhood Cancer (ICCC-3)[5]
- The third edition of the International Classification of Diseases for Oncology (ICD-O-3)[6]
- The tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10)[7].

All tumours were separately coded by two independent coders and double checked with logical analyses and automated coding systems from the German Childhood Cancer Registry.

5.4.2 Adaptations of the current database

The following fields have been added to the current database:

- Information about consent given by the patient or his/her parents to the data transfer from the clinic to the SCCR
- Information about patient registration: person entering the first notification into the database and date of entry.
- Validation of patient address: date when the patient address was validated; if information concerns patient or parent; result of the validation
- Details about the therapy protocol: exact study name, study group (e.g. COG, GPOH, SIOP), abbreviated study name, year when study was initiated, treatment regimen, modifications to the study protocol, information if patient was entered as a study patient or only treated according to a certain protocol but not entered into the study, comments

The following additional information from new sources has been added to the database and old information has been updated.

- Date of death was added for several patients after detailed review of information from the mortality statistics of the SFSO, local databases from the paediatric oncology clinics, and information from the cytogenetics database.
- Personal information (current address) has been updated in the course of the late outcomes in childhood cancer survivors research project. Each clinic was visited and details of patients were updated from the patient charts.

5.4.3 Improvement of the information form

Until recently information about new childhood cancer patients in each of the 9 paediatric oncology clinics had been sent to the SCCR on paper forms, which were entered into the electronic database

[5] Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, third edition. Cancer 2005;103(7):1457-67.

[6] World Health Organization. International Statistical Classification of Diseases for Oncology - 3rd Edition (ICD-O-3). Geneva: World Health Organization; 2000.

[7] World Health Organization. International statistical classification of diseases and related health problems - Tenth Revision. Geneva: World Health Organization; 1993.

and finally archived at the SPOG secretariat. To improve the quality of the information and enable electronic entry an interim form was developed on MS Excel. This form is used until the final data transmission form is available together with the new database.

6 Publications

We only report publications from 2005- 2007 closely related to the SCCR or publications with at least two authors from the SPOG. Additional publications related to the SPOG and the SCCR can be found on the SCCR-website: www.kinderkrebsregister.ch.

6.1 Peer reviewed publications

2007

Michel G, von der Weid NX, Zwahlen M, Redmond S, Strippoli MP, Kuehni CE. Incidence of childhood cancer in Switzerland: The Swiss childhood cancer registry. Pediatric Blood & Cancer, DOI 10.1002/pbc.21129.

Röösli M, Michel G, Kuehni CE & Spoerry A. Cellular telephone use and time trends in brain tumour mortality in Switzerland from 1969 to 2002. European Journal of Cancer Prevention. 2007 16(1):77-82.

2006

Kuehni CE, Zwahlen M. Commentary Commentary: Numerous, heterogeneous and often poor – the studies on childhood leukaemia and socioeconomic status. Int J Epidemiol 2006;35:384-5.

Brown AE, Leibundgut K, Niggli FK, Betts DR. Cytogenetics of pineoblastoma: four new cases and a literature review. Cancer Genet Cytogenet 2006;170:175-179.

Reid AG, Seppa L, von der Weid N, Niggli FK, Betts DR. A t(12;17)(p13;q12) identifies a distinct TEL rearrangement-negative subtype of precursor-B acute lymphoblastic leukemia. Cancer Genet Cytogenet 2006;165:64-69.

Schlapbach LJ, Aebi C, Otth M, Luethy AR, Leibundgut K, Hirt A, Ammann RA. Serum levels of mannose-binding lectin and the risk of fever in neutropenic pediatric cancer patients. Pediatr Blood Cancer, Dez 1, 2006

Wallach, M., Balmer, A., Munier, F., Houghton, S., Pampallona, S., von der Weid, N., et al. (2006). Shorter time to diagnosis and improved stage at presentation in Swiss patients with retinoblastoma treated from 1963 to 2004. Pediatrics, 118(5), e1493-1498. doi:10.1542/peds.2006-0784

Zucol F, Ammann RA, Berger C, Aebi C, Altwegg M, Niggli FK, Nadal D. Real-time quantitative broad-range PCR assay for detection of the 16S rRNA gene followed by sequencing for species identification. J Clin Microbiol 2006;44:2750-2759.

2005

Betts DR, Avoledo P, von der Weid N, Greiner J, Niggli FK. Cytogenetic characterization of Ewing tumors with high-ploidy. Cancer Genet Cytogenet 2005;159:160-163.

Betts DR, Cohen N, Leibundgut KE, Kuhne T, Caflisch U, Greiner J, Traktenbrot L, Niggli FK. Characterization of karyotypic events and evolution in neuroblastoma. Pediatr Blood Cancer. 2005 Feb;44(2):147-57.

6.2 Other Papers

2007

Diezi M, Tercier S, Osterheld M-C, Joseph J-M, Tumeurs rénales de l'enfant. Revue Médicale Suisse 2007;3:360-5

2006

Ammann RA. The SPOG 2003 FN Study on Children with Cancer and Fever in Neutropenia: Risk Assessment and Low-Risk-Adapted Therapy. Schweizer Krebsbulletin 26:278-280, 2006

Beck Popovic M, Joseph JM, Gross N. Neuroblastoma. Rev Med Suisse. 12;2:999-1004, 2006

Vajtai I, Kappeler A, Lukes A, Arnold M, Ridolfi Lüthy A, Leibundgut K. Papillary glioneuronal tumor. Pathol Res Pract 202:107-112, 2006

Von der Weid N, Beck Popovic M. Acute lymphoblastic leukemia in children and adolescents. Rev Med Suisse 2:873-876, 2006

Wagner HP, von der Weid NX. La maladie die Hodgkin de l'enfant: Un maximum de survie avec un minimum de séquelles. Rev Med Suisse 2:2812-2815, 2006

2005

von der Weid N. Spätfolgen nach Krebserkrankung und deren Therapie. Pädiatrie 2005;3:20-22,

Nobile L, Heinkel J. Bernasconi G , Rossetti G. Pulmonary Inflammatory Pseudotumor in a toddler. Krebsbulletin, June 2005: 140-143.

von der Weid N. Spécificités du cancer de l'enfant et de l'adolescent. Revue med suisse 2005.

von der Weid N, Beck Popovic M. Leucémie lymphoblastique aiguë de l'enfant et de l'adolescent. Revue med suisse 2005

7 Abbreviations

ACCIS	Automated Childhood Cancer Information System
COG	Children's Oncology Group, formerly Pediatric Oncology Group
GCCR	German Childhood Cancer Registry
GPOH	Gesellschaft für Pädiatrische Onkologie und Hämatologie
IACR	International Association of Cancer Registries
IARC	International Association of Research in Cancer
ICCC-3	International Classification of Childhood Cancer, Third revision
ICD-10	International Classification of Diseases, Tenth revision
ICD-O-3	International Classification of Diseases in Oncology, Third revision
ISPM	Institute of Social and Preventive Medicine, Bern
LCH	Langerhans cell histiocytosis
NRCT	National Registry of Childhood Tumours, Oxford, England
POG	Pediatric Oncology Group
SCCR	Swiss Childhood Cancer Registry
SES	Socio-economic status
SFSO	Swiss Federal Statistical Office
SPOG	Swiss Paediatric Oncology Group
VSKR /ASRT	Association of Swiss Cancer Registries
WHO	World Health Organisation

8 Appendix

8.1 Appendix 1: Classification of childhood cancer used by the SCCR

8.1.1 ICCC-3

The third edition of the International Classification of Childhood Cancer (ICCC-3) represents the standard for presentation of international data on childhood cancer incidence and survival[8]. It applies the rules, nomenclature and codes (morphology, topography and behaviour) of the ICD-O-3. Furthermore, ICCC-3 categories are defined in conformity with international classifications of the pathology and genetics of childhood cancers. In the ICCC-3, three hierarchical levels have been developed: level one consists of 12 main diagnostic groups and level two of 47 diagnostic subgroups. These two levels of the ICCC-3 allow standardised comparison of the broad categories of childhood tumours. Level three, an optional "extended" classification, comprises two to eleven divisions of selected diagnostic subgroups. The division of some diagnostic subgroups, e.g. leukaemias and Non-Hodgkin lymphomas, reflects the availability of detailed cytogenetic or molecular information that permits homogeneous groups of tumours to be distinguished within them and thus allows their separate study. Most childhood cancer registries only use level one and two. Only malignant neoplasms are classified in ICCC-3, with the exception of non-malignant intracranial and intraspinal tumours. Tumours known to occur only rarely in young patients are also included in ICCC-3. The ICCC-3 is used if data are compared with other childhood cancer registries.

8.1.2 ICD-O-3

The third edition of the International Classification of Diseases for Oncology (ICD-O-3) [9] has been developed by a working group hosted by IARC/WHO. The morphology code for neoplasm has been revised, especially for lymphomas and leukaemias. In contrast to the ICD-10 classification, ICD-O-3 uses only one set of four characters for topography (based on the malignant neoplasm section of ICD-10). The topography code remains the same for all neoplasms of that site. The behaviour code is incorporated as the fifth digit in the morphology field. It identifies whether the tumour is malignant, benign, of uncertain or unknown behaviour, in situ, presumed to be primary or secondary. ICD-O-3 is used to compare data with general cancer registries.

8.1.3 ICD-10

The International Statistical Classification of Diseases and Related Health Problems (ICD)[10] permits the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different regions and at different time periods. The ICD has become the international standard diagnostic classification for all general epidemiological purposes. The ICD-10 classification comprises three volumes: Volume 1 contains the main classifications; Volume 2 provides guidance for users of the ICD; and Volume 3 is the alphabetical index to the classification. Classification is divided into 21 chapters. The first character of the ICD code is a letter. Each letter is associated with a particular chapter, e.g. the letter D is used in both chapter II "Neoplasms" and chapter III "Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism". The topography code in Volume 3 describes the site and the behaviour of the neoplasm: malignant,

[8] Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, third edition. Cancer 2005;103(7):1457-67.

[9] World Health Organization. International Statistical Classification of Diseases for Oncology - 3rd Edition (ICD-O-3). Geneva: World Health Organization; 2000.

[10] World Health Organization. International statistical classification of diseases and related health problems - Tenth Revision. Geneva: World Health Organization; 1993.

secondary or metastatic, in situ benign, or unknown behaviour. The morphology codes listed in Volume 1 are the same as those used in the special adaptation of the ICD for oncology, the ICD-O-2.